NINDS CDE Resource

Quality of Life in Neurological Disorders (Neuro-QOL) Pediatric Functional Health

Availability:	Although the Neuro-QOL measures have been tested in two large calibration studies with disease-based and community dwelling samples, the calibrated short forms are currently being administered in a multi-site clinical validation study. Until this study has been completed and the Neuro-QOL measures are released into the public domain, investigators or groups wishing to use them in their current or future study may do so if they agree to provide the Neuro-QOL study team with item-level data derived from their respective study, which will be used to evaluate the performance of Neuro-QOL items in different neurological conditions and trials. For additional information and to obtain Neuro-QOL instruments, please visit Quality of Life in Neurological Disorders Instrument Link
Classification:	**Exploratory:** Spinal Cord Injury (SCI)-Pediatric
Comments / Special Instructions	The development and validation of the Neuro-QoL measures did not include children.

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Short Description of Instrument:	**Purpose:** The Neuro-QOL is a Patient Reported Outcome (PRO) measurement system designed for neurologically impaired populations. Neuro-QOL seeks to incorporate patient reported outcomes of functioning, such as social, psychological, and mental well-being. **Overview:** Contains 10 calibrated item banks with Likert-style items. Several of the item banks are linked with the Patient Reported Outcomes Measurement Information System (PROMIS). Neuro-QOL item banks cover the following domains: Mobility/Ambulation, ADL/Upper Extremity, Depression, Anxiety, Positive Psychological Functioning, Stigma, Perceived and Applied Cognition (includes communication), Social Role Performance, Social Role Satisfaction, Fatigue, Personality and Behavioral Change and Sleep Disturbances. Pediatric Functional Health Domain Framework: Comprised of the following domains: lower extremity function (mobility) and upper extremity function (fine motor, ADL) **Time:** Administered as short-forms or as Computer Adaptive Tests(CAT). Administration time is less than 5 minutes per sub domain (total time for short form across all domains is about 30 minutes). **Scoring** Patient reads Likert items on computer screen and responds. Embedded in several of the Neuro-QOL domains are a significant number of PROMIS items. Because of this, a PROMIS equivalency score can be derived for all individuals who complete the Neuro-QOL measures. **Psychometric Properties:** Neuro-QOL is a clinically relevant and psychometrically robust health-related quality of life (HRQL) assessment tool for adults and children. It is responsive to the needs of researchers in a variety of neurological disorders and settings and facilitates comparisons of data across clinical trials in different diseases. **Other Important Notes:** The Neuro-QOL is designed to be a common outcome variable across clinical trials research sponsored by the NINDS. It has been tested in large samples of individuals from the general population and diverse neurologically impaired populations. Validation with stroke patients is underway. **Strengths:** Neuro-Qol includes multiple banks and short forms that cover a variety of domains. These domains were initially developed for adult patients with ALS, multiple sclerosis, Parkinson's disease, and stroke and for pediatric populations with epilepsy and muscular dystrophy (e.g., Duchenne Muscular Dystrophy). **Weaknesses related to DM:** The instruments include CATs, short forms, and scales. These instruments and domains were not developed specifically for myotonic dystrophy or validated in this population.

References:	TBI CDE Working Group (2010). CDE Recommendations - Listing of the Core, Supplemental and Emerging Measures for each Outcome Domain. NINDS Common Date Elements Traumatic Brain Injury Disease page (accessed March 10, 2010). Neuro-QOL Bank Development and Construction. Quality of Life in Neurological Disorders Instrument Link (accessed March 10, 2010). **HD:** Carlozzi, N. E. (2010). Examining Health-Related Quality of Life in Huntington's Disease. Advances in Outcome Measures for Neurologic Disorders, Symposia presented at the ACRM-ASNR Joint Educational Conference, Montreal, Quebec, Canada. http://www.asnr.com/files/public/2010PrelimProg-Final.pdf. Carlozzi, N. E., H. McGowan and D. S. Tulsky (2010). Extending the Neuro-QOL to Huntington's Disease (HD): The development of the HD-HRQOL. International Society for Quality of Life Research 17th Annual Conference, London England. http://www.isoqol.org/UserFiles/file/2010_conference_program.pdf. Carlozzi, N. E. and D. S. Tulsky (2011). Health-related quality of life in Huntington disease. In: Abstracts for the 2011 World Congress on Huntington's Disease, 11-14 September 2011, Melbourne, Australia. Clin Genetics 80(Suppl s1): 37–38. Carlozzi, N. E. and R. E. Ready (2011). Health-related quality of life in Huntington's disease. Quality of Life Measurement in Neurodegenerative and Related Conditions. C. Jenkinson, M. Peters and M. B. Bromberg. Cambridge, UK, Cambridge University Press: 71–81. Carlozzi, N., D. Tulsky, D. Garcia, E. Gray, E. A. Hahn, J. Hammel, H. Hollingsworth, S. Jerousek, P. Kisala, J. Lai, S. Magasi and A. Heinemann (2012). Developing patient reported out-come measures of environmental factors affecting participation in medical rehabilitation. Abstract presented at: Fortieth Annual Meeting International Neuropsychological Society February 15-18, 2012, Montréal, Québec, Canada., pp. 67–68. Available at: http://www.the-ins.org/includes/ckfinder/userfiles/files/Linked%20Program_abstracts.pdf. Carlozzi, N. E. and D. S. Tulsky (2013). Identification of health-related quality of life (HRQOL) issues relevant to individuals with Huntington disease. J Health Psychol 18(2): 212–225. Cella, D., C. Nowinski, A. Peterman, D. Victorson, D. Miller, J. S. Lai and C. Moy (2011). The neurology quality-of-life measurement initiative. Arch Phys Med Rehabil 92(10 Suppl): S28–S36.